**Listening Session WHCOA**
**Submitted for the Health and Medicine Policy Research Group**

The Health and Medicine Policy Research Group (HMPRG) is grateful for this opportunity to raise what we consider a difficult but important issue for the forthcoming WHCOA: What ought the role of public funding be in helping people with modest incomes (but not poor in standard definitions of the term) cope with their own and their families' LTC needs? These individuals were shopkeepers, retail clerks, nursery school teachers, and small business owners. Some may have worked in factories; others were salesmen or repairmen. Today, people like these work in the service sector. They also staff our many small non-profit organizations and wait on us in restaurants and cu tour hair or do our nails.. We are those people or they are our parents; or we know who they are. Let's assume that they (we) have worked hard and played by the rules. But they (we) didn't or don't have sufficient resources to save very much for the proverbial rainy day and now they (we) are getting older. They (we) are either retired or thinking about it and so whatever is left over after bills are paid is directed toward retirement. Some economists have described this group as "Tweeners," since they do not have the resources to pay out of pocket and do not qualify for Medicaid without spending down. Another, slightly poorer group, are described as the "Medicaid-bound." Over the next few decades many factors will shape the ability of both groups to afford long-term care.

We—that is HMPRG—had the privilege of talking to more than 300 of these people at 13 community forums we sponsored in 2003 (a full report is available on our web site: www.hmprg.org) and in the fall of 2004 we convened 4 focus groups. In the focus groups we met with older people and with family members who were caring for their older relatives. Some elder participants were already receiving services. At the forums we invited discussion about 4 primary issue areas: access to and organization of services; family concerns; financing; and workforce. We learned, perhaps not surprisingly, but certainly emphatically, that people were very worried about what they would do if they needed help. Or, they were helping disabled family members and were very anxious about how they were going to make it. Caregiver issues and financing ones are inevitably linked. Middle class people must rely on family members for care since they are too "rich" for public programs and too "poor" to purchase help. This factor importantly sets them apart from the more affluent who hare able to buy the help that they need. In our forums several told stories about having to place relatives in a nursing home when their own health failed.

If America is built on the strength of its middle class—and we are not defining that as some have done—people earning in excess of $100,000—then we are letting them down just when they might need society's help the most. Think of the family of four with a median income of $62,732 —that is who we are talking about.

Some words from the forums might capture the sentiments of these people. One couple, both in their 70s, were very proud that her mother continued to live independently—that is, with both of them going to her house at least twice a day to help her with food and

dressing. When we asked them how they would take care of themselves, they hesitated and said, "our daughter, we suppose." They had no idea and they had never thought about LTC insurance because they never had any spare money.

At another forum, a middle-aged woman described caring for her mother who had Alzheimer's disease. She herself was over 60 and had recently broken her leg and was on medical leave from her job She was unable to get help for her or her mother from any public program because their assets were too high but just barely so. They were ineligible for Medicaid and the state's somewhat more generous Community Care Program. She wondered if she should cash in the CD which put her marginally over the top in terms of income.

There was bitterness at many forums. "We worked hard and paid taxes all our lives and now that we need help it's not there." "Why is LTC any different than needing coronary artery by-pass surgery?" "People paid taxes all their lives and are left fighting for crumbs." They often felt abandoned just when they needed help the most. One woman at a senior center asked, "Doesn't anyone think of the common good any longer?" The notion that LTC was a shared rather than an individual risk was a recurrent theme.

We could go on but these examples suggest some of the views that we heard. They were pervasive, expressed forcefully and often poignantly. What we heard also affirmed what research has also suggested. People do not seek help unless they really need it. "It is hard enough to need help; it is even harder to ask for it" said one 85 year-old woman in rural Illinois.

We also heard what may seem surprising. Many people insisted that they would be willing to pay more taxes if they could be guaranteed that some assistance with the costs of LTC would be available when they needed it. At one site, the wife of a retired professor suggested taxing all retirement income. Others recommended an income tax check-off. No one seemed opposed to taxation if they felt it would more broadly share the risk of LTC expenses. While we cannot suggest that these forums reflect a representative sample from which one can make valid generalizations, it is clear that as a society we have too quickly assumed that taxation is the nemesis and that anyone who suggests it is in danger of destroying his or her political future. Extra sources of funding are worth exploring.

So what do we recommend? It seems quite clear that states alone can't respond to the LTC needs of their populations. Medicaid is already burdened and general revenues are in short supply as long as the possibility of any tax increase is off the table. The limitation on the ability of states to pay for LTC while they also have to assist poor women and children for whom the program was initially designed, is apt to increase as the federal government tries to reduce its share of Medicaid spending. It is equally clear that at least in the foreseeable future, any further expansion of Medicare is unlikely. Evidence also suggests that at least in the short term, the private LTC market will have limited appeal. Even in states that offered special incentives, the purchasers were those who would have bought the policies anyway. Unless LTC insurance is bought when

people are in their 30s and 40s when such policies are less costly than later, the costs can become prohibitive especially if individuals have pre-existing conditions that drive up premium costs. But at earlier ages, individuals and families have other more immediate demands on their income.

While these comments only scratch the surface of the financing issue, we recommend the following:

1. Sponsor sessions at the WHCoA and at pre-conference sessions that:
    a. Facilitate discussion about the goals of our society for older people who have chronic care needs; and
    b. Explores the question of how LTC ought to be financed;
2. Invite others to go to their communities and ask questions about risk sharing and the question of whether LTC is a private or a societal responsibility or a combination of the two; and
3. Then inquire how that mixture can be achieved.
4. Develop a campaign to educate the media, ie, oped. pieces, letters to the editor, meetings with editorial boards about the costs of LTC and alternative ways of financing it.
    a. The IRA is an example of a product that initially wasn't well known, but with education has become part of people's retirement planning. People don't understand Long-term Care Insurance and perceive it as nursing home insurance.
    b. Ask for consideration of this question: What if a common pool was created in which a public long term care insurance plan was developed rather than encouraging individuals to protect only themselves and their families?
5. For those who chose to buy LTC insurance, create guarantees:
    a. That community ratings will be used;
    b. That pre-existing conditions will not make policies unavailable—make policies available to any willing purchaser--or unaffordable;
    c. That if a company folds or leaves the LTC insurance business that policies are honored through some to be established mechanism;
    d. That policies are clear about what they do/do not offer;
    e. That renewals are automatic if premiums are paid.
    f. That state insurance commissions will exercise oversight and mandate that the benefits are clearly stated and so not overlap with any other benefits.
    g. Further, explore methods of combining public/private insurance and examine who benefits/who loses if some tax credits are made available for the purchase of LTC insurance.
6. Explore various sliding scale mechanisms so the people we are describing can buy into public programs at a cost that is significantly less than private pay;
7. Don't underestimate the willingness of the American population to take care of its older and disabled members;
8. Examine funding mechanisms at the state level even if it means a special tax;

9. Adequately support family members by building upon the National Caregiver initiatives so that more services and even financial support are available to caregivers.
10. Incentives need to be built into the system to encourage people to use home care, and there will need to be more caregivers available.
11. More systemic change should:
    a. Broaden eligibility for Medicaid
    b. Include LTC in the Medicare program
        i. Consider ways to pool resources through federal taxation to cover LTC (Explore options other than the payroll tax because of its regressive features)
        ii. Develop a progressive cost sharing plan (as with Medigap policies, people can buy supplemental policies or pay out of pocket for the co-pays or deductibles)

Submitted by Martha Holstein, Ph.D. and Phyllis Mitzen, MSW